A I D S TREATMENT N E W S

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Contents

AIDS Treatment News

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Statement of Purpose:
AIDS Treatment News reports on experimental and standard treatments, especially those available now. We interview physicians, scientists, other health professionals, and persons with AIDS or HIV; we also collect information from meetings and conferences, medical journals, and computer databases. Long-term survivors have usually tried many different treatments, and found combinations that work for them. *AIDS Treatment News* does not recommend particular therapies, but seeks to increase the options available.

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recognize medical use. This amendment received 152 votes in Congress last year.

ADVAX, New DNA Vaccine in Human Trial; HIV-Negative Volunteers Needed in New York City or Rochester, NY Areas.....

HIV-negative volunteers are needed for an important vaccine trial.

Drug Resistance Workshop (June 2004) Summaries Available.....

Two in-depth reports summmarize the International HIV Drug Resistance Workshop, which occurred this year in Tenerife, Canary Islands, Spain.

Bangkok Conference, July 11-16; Getting News Online

The XV International AIDS Conference in Bangkok, Thailand July 11-16 will be the largest AIDS conference of the year and probably the largest ever; already 10,000 abstract presentations have been submitted, more than to any other AIDS conference. Fortunately there will be plenty of good reporting online, both during the conference and afterwards, for those who cannot go (and for those who do go as well, as no one could attend more than a fraction of the public meetings, many of which happen simultaneously).

Of the following news sources, only the first two are specific to the conference itself. The rest provide AIDS reporting at any time, whether or not any conference is happening, and we recommend them for AIDS-related news.

Note: Web sites change over time. If a link below does not work, try going to the home page (generally by using the name through the .org or .com, ignoring what follows), then try to find the information by looking around the site. If the home page does not work, then usually the site is down temporarily, and will be working again within a day.

Bangkok Conference News

* The Kaiser Family Foundation's kaisernetwork.org "will provide daily coverage of the XV International AIDS Conference -- including news summaries, interviews, webcasts, transcripts, and slide presentations from selected sessions." KFF has long provided useful and credible AIDS news reporting through its Kaiser Family Foundation Daily HIV/AIDS Report (see below). You can sign up for the conference-specific coverage (only for the week of July 11-16, 2004) at http://www.kff.org/aids2004/

* The official Web site of the Bangkok conference should have the searchable abstracts online during the event, as well as background information like the program and schedule. But historically the official conference sites have not otherwise be been very useful in reporting the scientific and medical news from these meeting. The Web address is http://www.aids2004.org/

General News (Mainstream Newspaper, Newswire AIDS Reports)

* The AEGIS Daily Briefing collects important news reports from a variety of mainstream sources, at http://www.aegis.org/

* AIDSMEDS.COM has mainstream news at http://www.aidsmeds.com/news/TopStories.htm

* NATAP, the National AIDS Treatment Advocacy Project, has a few selected AIDS news items at http://www.natap.org/ (click on "News Updates").

* You can subscribe to a weekly email newsletter of mainstream and original reporting at http://www.centerforaids.org/rita/weekly.htm

In-Depth General and Medical AIDS Reports

* The Kaiser Family Foundation Daily HIV/AIDS Report writes its own articles specifically on AIDS and publishes them each weekday. You can see the current day's publication at http://www.kaisernetwork.org/daily_reports/rep_hiv.cfm. This page also links to an archive search, so you can find articles by key word. You can also subscribe to receive a daily email with a summary of each article that day, and a link to the full report.

* Clinical Care Options has CME training modules and other materials written primarily for AIDS physicians and other medical professionals. In addition to the HIV/AIDS site, it also has a hepatitis site, and an oncology (cancer) site as well. The HIV site is at http://www.clinicaloptions.com/hiv/

* Many other sites may have in-depth coverage during or after the International Conference, as well as other AIDS news. Here are several to check:
http://www.hivandhepatitis.com/
http://www.thebody.com/
http://www.iapac.org/
http://www.natap.org/
http://hivinsite.ucsf.edu/
http://www.hdnet.org/home2.htm (hosts international discussions)
http://www.unaids.org/ (United Nations)

U.S. Researcher Starts Treatment Fund in Uganda: Interview with David Bangsberg, M.D., M.P.H.

Dr. David Bangsberg studies HIV treatment access, adherence, and outcomes in San Francisco, among persons in resource-poor settings who are homeless or at risk for mental illness or illegal drug use. His group was invited to Uganda to study treatment outcome in resource-poor settings there. Since institutional monies would not pay for drugs for treatment, which cost about $300, a year Dr. Bangsberg set up the Family Treatment Fund to receive tax-deductible contributions to treat some of the Ugandans he is working with. More information can be found at http://familytreatmentfund.ucsf.edu/.

AIDS Treatment News asked Dr. Bangsberg about his research and about the

new fund.

ATN: Can you tell us how your work in San Francisco led to the work in Uganda?

Dr. Bangsberg: The focus of our group is the relationship between poverty and treatment outcomes in HIV-infected people. We studied a group of homeless people in San Francisco, in the Tenderloin district, to look at how well people who are homeless or marginally housed, with high rates of mental illness and drug use, access HIV healthcare and adhere to HIV therapy, and how that translates into improved health outcomes.

We had established that many HIV+ homeless patients do well when prescribed HIV antiretroviral therapy in the U.S. While HIV and poverty is a major and complex problem in the U.S., the major burden of HIV infection as well as the burden of poverty in this world is not in the Tenderloin of San Francisco but in sub-Saharan Africa. We received an invitation to help Makerere and Mbarara Universities develop a research program in HIV treatment adherence and treatment outcomes in Kampala, Uganda. With that research agenda we raised money to conduct prospective trials of how well patients there were adhering to HIV therapy, and how well their adherence translates to improved health outcomes. We started studying the only patients who are receiving HIV therapy, largely those who are purchasing their own. They are mostly obtaining a generic HIV fixed-dose combination, Triomune, which is a co-formulation of d4T, 3TC, and nevirapine -- in one pill administered twice a day.

We looked at how households finance HIV treatment, how well patients adhere to it, and how this relates to treatment outcomes -- delayed progression to AIDS, antiretroviral suppression, avoiding drug resistance, and survival. We were successful in funding these research projects.

As we raised money for research in AIDS, it became clear that there is also a responsibility to make sure peoples' lives are improved by having better access to therapy. We interview families in our studies who pool their money across twelve or fifteen family members to secure enough therapy for one of many HIV-infected people. In Uganda the median income is about $30 a month, which is the same as the price of generic HIV therapy. Families are making incredible sacrifices, and sometimes only one family member is receiving treatment, and others members die without it.

Three hundred dollars per person per year is a small amount of money by Western standards, though it's a lot of money in Uganda. If we can raise hundreds of thousands of dollars to do research on these treatment outcomes, we feel that hardworking, well-meaning persons will be able to raise money to actually buy medications, which will do more for the individuals than studying outcomes on a larger population level.

In this study Dr. Oyugi found it was possible to measure adherence quite accurately in resource-poor settings, among these patients who are purchasing generic drugs for their therapy. Preliminary results suggest that levels of adherence are quite high. Several other reports from Africa about patients receiving HIV therapy to date suggest that adherence is high and probably better than that in the general population in the U.S. So adherence is not a barrier to successful treatment outcomes. One of the big challenges is coming up with enough money to make sure that people have access to therapy.

ATN: And antiretroviral drugs cost about a dollar a day in Uganda.

Dr. Bangsberg: Realizing that a little money goes a long way, we set up the Family Treatment Fund to raise money to directly purchase HIV therapy for those people who would otherwise be unable to afford therapy, and would likely die in the next six to twelve months without it. Other medical care is already available free to patients through Makerere University.

A group of Ugandans make the decision of who are the best candidates for treatment, based on these two guidelines. When we raise $2000, we have enough money to provide five years of treatment for a person. We believe five years is important because we hope that the antiretroviral landscape will change dramatically in the next five years, and this treatment will bridge them into a time when people will have better

access to antiviral therapy.

And also, even if access doesn't improve in the next five years, most of these people are members of families, often parents who are caring for children, often children of relatives who died from AIDS. If we can keep the parents alive for five more years, it allows five more years of parenthood, which for a child is an incredible gift. So the five-year benchmark is both a bridge to the future, and also an immediate benefit by giving time to raise a family, to keep a family intact. Therefore the name Family Treatment Fund.

ATN: You organized this fund?

Dr. Bangsberg: I founded the Family Treatment Fund with help from leaders in HIV care in San Francisco: the Department of Public Health, the Health Commission, business leaders here in San Francisco, and other people who have had experience in nonprofits. This is new for me; I am a researcher who studies health outcomes, I've never been a philanthropist.

ATN: Is the Family Treatment Fund under the University of California?

Dr. Bangsberg: The University of California San Francisco is our fiscal agent; it manages the donations and makes sure they are used appropriately. Any donation is tax deductible.

The Web site is http://familytreatmentfund.ucsf.edu/. Donations can be made either by checks payable to the University of California San Francisco for the Family Treatment Fund, or by credit card online or by phone through the University's donation page. The goal of the Family Treatment Fund is to raise $1.4 million to put 500 people on antiretroviral treatment for five years.

ATN: Why did you have to start a new organization to raise funds for treatment?

Dr. Bangsberg: The major players in HIV are not natural funders for generic antiretroviral therapy. Big pharma, which has made major contributions to improving HIV therapy, is not a natural partner in making generic HIV drugs available.

The other major player is the U.S. National Institutes of Health, and it has not made it possible to directly fund antiretroviral treatments as part of research studies. The Gates Foundation has prioritized prevention rather than treatment. Hopefully the World Bank funds, and the money the Bush Administration has pledged, will better translate into access to antiretroviral therapy. But it will take time for these pledged funds to actually lead to people receiving medications.

The Family Treatment Fund is small and very flexible. We can take a donation and directly purchase the medications, and get them to the person within a month or two of receiving the money. We see ourselves as small but flexible and responsive, able to bridge the gap to the time when therapy will be more accessible on a broader scale, funded by major institutions.

ATN: Couldn't pharmaceutical companies donate their own drugs?

Dr. Bangsberg: The introduction of generic therapy has led to dramatic reductions in price for branded therapy as well. The companies saw the new competitive landscape, and reduced their prices many fold to make them more competitive with generic therapy. Triomune is the least expensive antiretroviral therapy available anywhere in the world. But pharma has responded with dramatic reductions in their prices, also.

You might ask, how well do these drugs work? There have been several early reports on Triomune therapy. And these early reports suggest that we get good viral suppression and CD4 responses, and delayed progression to AIDS and death. So we think this is very effective antiretroviral therapy. It is certainly an accepted option in the U.S. to use this branded combination therapy, and we have no reason to believe that the generic co-formulation performs any less well.

ATN: How much can private contributions do?

Dr. Bangsberg: When people hear about the international HIV pandemic and learn about it, they often come to feel that the problem is so large that they are paralyzed, and unable to make a meaningful

contribution. The pandemic is beyond comprehension in its enormity, and is the most serious global issue we have at this time. I think the Family Treatment Funds provides a way for someone to make a very tangible contribution to this pandemic. Thirty dollars provides a month of antiretroviral therapy; $2000 provides five years of therapy for one person.

The message we want to get across is one of hope, and how an individual can help one person's life in this pandemic. It breaks the problem down to one person at a time, one contribution at a time, so people can contribute in a meaningful, powerful, and important way.

ATN: When people start doing this, maybe they can also lobby governments, corporations, and other institutions?

Dr. Bangsberg: We believe wider access to antiretroviral therapy will be politically powerful in local governments and communities. When someone sees a person go from 50 pounds to 150 pounds with several months of treatment, communities may start demanding it. So we think that even small demonstrations of success will begin to have important political impact.

We are optimistic that these programs will improve access to therapy. We certainly hope that governments and other organizations can put us out of business in trying to raise money to treat individual people. But until that time there is a need for small, flexible, responsive organizations to provide treatment to as many individuals as possible.

* * * * *

Note: As of June 18, 2004 the Family Treatment Fund had raised $22,000 and had ten people on therapy. For every $2,000 they raise they put another person on antiretroviral treatment, funded for five years; priority is given to patients likely to die in six months without antiretrovirals. Ninety four percent of contributions go to pay for the drugs, through wire transfer to pharmacies in Uganda; the other 6% is for fiscal sponsorship by the University of California San Francisco. For more information or to make a contribution, contact the Family Treatment Fund, http://familytreatmentfund.ucsf.edu/.

President Bush on AIDS: More Questions Than Answers

Comment by John S. James

On June 23, 2004, President Bush spoke on AIDS in Philadelphia, at the same African American church where he also spoke on July 4, 2003. A transcript of this year's talk is at http://www.whitehouse.gov/news/releases/2004/06/20040623-4.html -- along with a White House fact sheet, and a discussion led by Carol Thompson, White House Office of National AIDS Policy.

The high-profile attention to AIDS is welcome, and the announcements look generous when reduced to headlines. But they leave major questions unanswered. The quotations below are from the fact sheet, which listed four announcements the president made in his speech:

* "Immediate availability of $20 million in new funding to deliver life-saving drugs to the men and women in the United States living with HIV/AIDS who are waiting today for HIV-related medication;"

This is welcome if it will get treatment for some of the over 1,600 Americans now on waiting lists for antiretrovirals through the AIDS Drug Assistance Program (ADAP). But there is good information on the cost of meeting the need, and the $20 million promised is less than 20% of the emergency funding required to end the waiting lines for this fiscal year. So far at least 25 U.S. senators have signed a letter calling for a $217 million increase for fiscal year 2005, plus a $122 million emergency increase to end the waiting lines now through March 30, 2005 (when ADAP can use the 2005 funding).

Also, the $20 million is not new money but will come from some other health funding. As of late June we do not know what other program will be cut.

Another long-term problem is that the ADAP program is supposed to be supported

jointly by the Federal government and the states. The new money will largely go to those states that have failed to do their part (since they tend to have the longest waiting lines), removing incentive for states to contribute. While the central concern is getting treatment to the individuals who need it, we also need plan for sustainability, not just looking good before the election.

* "Support for the reauthorization of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act based upon the principles of focusing Federal resources on life-extending care; ensuring flexibility to target resources to address areas of greatest need; and ensuring results;"

The focus on life-extending care means "such as anti-retroviral drugs, doctor visits, and lab tests" (quoted from the fact sheet). Does this mean that cost-effective services like case management will no longer be funded through Ryan White, and almost all of the money will go to pharmaceutical companies instead?

Also, Bush wants his Administration to control how Ryan White money is allocated among different parts of the country. But this Administration has politicized science probably more than any other in history. How do we know that the money will not be directed to reward political supporters even if their programs were not working? This is happening already with abstinence-only HIV prevention programs.

* "Second distribution of available funding for the focus countries of the Emergency Plan for AIDS Relief -- $500 million -- will soon be on its way to organizations working in the field to provide antiretroviral therapy, promote prevention, care for orphans, and build the health system capacity in Africa and the Caribbean;"

This sounds generous in the headlines, but this money was appropriated by Congress and should have been spent long ago. The main reason for the delay is that the Bush Administration largely rejected the Global Fund created by the United Nations, and set up its own system instead -- allowing it to use AIDS funding to pressure countries on unrelated issues.

* "Vietnam as the 15th focus country in the Emergency Plan."

We have no information on the merits of directing funding to Vietnam instead of some other country. But clearly the announcement works as compassion PR; Bush said in his talk, "We're putting a history of bitterness behind us with Vietnam."

The president also mentioned condoms "when appropriate," while much more strongly emphasizing abstinence. We are hearing that on the ground, "where appropriate" means restricting condom programs to sex workers or other marginalized populations -- and that countries are being told not to ask for condoms when applying for U.S. HIV funding.

Related: Bangkok, WHO, TAC

* Bush did not mention that his administration recently stopped 28 researchers from the U.S. Centers for Disease Control from attending the International AIDS Conference in Bangkok in July, forcing the withdrawal of about 40 scientific papers, after pressure against the Conference from right-wing members of Congress -- or that his administration is demanding that the World Health Organization get political approval before inviting any U.S. government scientist to WHO scientific meetings.

* Possibly by coincidence, the president spoke one day before the global day of demonstrations to invest in heath not war, called by the Treatment Action Campaign (TAC) of South Africa for June 24. From the call:

> "In January 2003, the Bush Administration promised $15 billion over the next five years to alleviate the HIV epidemic. This was cautiously welcomed by human rights and AIDS organizations. Yet the expenditure approved by the US Congress as part of this commitment for 2004 is only $2.4 billion. The total

amount of US aid money for 2004 is $17.55 billion. Yet the military budget approved for 2004 is already $368.2 billion, an amount that does not reflect the $87 billion war supplemental requested by the Bush Administration. Much of this military budget is being used to fight the so-called War Against Terror and to sustain the occupation of Iraq. We acknowledge the threat of terrorism. However, the most important and widespread threats to global security are the ones exacerbated by poverty and lack of development: the HIV, malaria and tuberculosis epidemics, as well as malnutrition. Alleviating these problems together with promoting human rights and negotiating solutions to world problems through international institutions is the best way to ensure long-term global security."

The full text of TAC's call is at http://www.tac.org.za/HealthNotWar.htm. By June 28, volunteers had compiled and circulated links to 125 news reports from around the world on the Health Not War demonstrations.

Abstinence, Abstinence-Only, Faith-Based, and the Psychology of Stigma

by John S. James

The June 23 talk by President Bush in Philadelphia (see "President Bush on AIDS: More Questions Than Answers" in this issue) raised deeper issues that need attention.

* There is common ground on abstinence; the problem is with abstinence-only (a phrase Bush did not use in his talk). Everyone agrees that not having sex is the most certain way to prevent sexual HIV transmission -- and few if any object to teaching that. But it certainly does not follow that abstinence-only prevention programs are best -- since many clients will not remain permanently abstinent, and the issue is what happens when they do not. Marriage is no magic answer, and in fact is a serious HIV risk factor for women in some societies. And the dynamics leading to sex vs. those leading to marriage can be very different -- especially in today's world where sexual maturity comes earlier, while the ability to support a family comes increasingly late in life, if ever.

Maybe we should remind the public that everyone alive today is here because every single one of his or her direct ancestors, throughout all of human history, had sex. In thousands of human generations not a single ancestor of anyone alive maintained sexual abstinence 100% (with a few exceptions in the last decades only, through modern fertility technologies). Those who believe in evolution will understand that so compelling a record will be hard to override by some organization's abstinence-only program. Yes, most people can be abstinent at critical times, reducing the risk of HIV infection, and this should be encouraged. But we cannot expect abstinence-only programs to work for everyone. Nor should we use HIV as a weapon to force people to conform, or as a means of execution when they do not.

* While the term "faith based" became prominent in the year 2000, religious organizations have been an integral part of the AIDS movement for many years. Organizations like Siloam (praised by President Bush), Catholic Charities, The Balm in Gilead, AIDS Interfaith Network, and many others have done excellent work. But unfortunately most churches have been unwilling to help -- a problem by no means limited to religious organizations.

Over the years I have found that most "AIDS stigma" (in the U.S. at least) stems from men's fears that if they get involved or help in AIDS, people may think that they secretly have AIDS or are gay. That suspicion can be a problem whether it is true or false (except of course for those who are already open about being gay and HIV-positive). This simple psychological dynamic explains the continuing difficulty of mobilizing churches, governments, and others to take obvious steps to prevent the worldwide catastrophe that has occurred. Compare the speed of mobilization against AIDS with that against legionnaires disease or SARS when they had killed thousands of times fewer people. Those diseases could get